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Using Qualitative Research to Identify and Address the Unique Needs of Caregivers of Persons with Alzheimer's Disease

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Abstract

This paper reviews articles describing qualitative research that explores the unique needs of caregivers of patients with Alzheimer's disease. Qualitative research methodologies used in these studies include hermeneutic phenomenology, descriptive studies with focus groups, and individual interviews. Researchers identified needs and concerns unique to caregivers of persons with Alzheimer's disease including the need for knowledge about the disease, care recipient and caregiver issues, resource needs, and coping post-nursing home placement. Suggestions for addressing the needs were given by study participants. Implications for nurses and other professionals working with caregivers of persons with Alzheimer's disease were addressed. The importance of qualitative research in bringing understanding of the essence of caregiving of persons with Alzheimer's disease is well-documented in this review.

Keywords

Alzheimer's Disease, Caregiving, Coping, Skill Development, and Qualitative Research

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Using Qualitative Research to Identify and Address the Unique Needs of Caregivers of Persons with Alzheimer's Disease

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This paper reviews articles describing qualitative research that explores the unique needs of caregivers of patients with Alzheimer's disease. Qualitative research methodologies used in these studies include hermeneutic phenomenology, descriptive studies with focus groups, and individual interviews. Researchers identified needs and concerns unique to caregivers of persons with Alzheimer's disease including the need for knowledge about the disease, care recipient and caregiver issues, resource needs, and coping post-nursing home placement. Suggestions for addressing the needs were given by study participants. Implications for nurses and other professionals working with caregivers of persons with Alzheimer's disease were addressed. The importance of qualitative research in bringing understanding of the essence of caregiving of persons with Alzheimer's disease is well-documented in this review. Key Words: Alzheimer's Disease, Caregiving, Coping, Skill Development, and Qualitative Research

Alzheimer's disease affects an estimated 5.3 million people in America (Alzheimer's Association, 2009). By 2029, all baby boomers will be at least 65 years of age. It is predicted that the number of cases of Alzheimer's disease will double every twenty years (Alzheimer's Association). Many Americans with Alzheimer's disease are cared for by family members. Caregiving of people with Alzheimer's disease can be very difficult. The demand of caregiving has a significant impact on the physical and emotional health of the caregiver.

Caregivers must provide various levels of care for the person with Alzheimer's disease. At the beginning of the disease, responsibilities frequently include shopping, meal preparation, transportation, oversight of medication, and assistance with financial and legal affairs. With progression of the disease, the person with Alzheimer's disease may require assistance with activities of daily living including bathing, feeding, dressing, and toileting. Wandering becomes a problem for many with Alzheimer's disease, and supervision 24 hours a day, seven days a week, may be needed to insure safety. When the burden of caregiving becomes greater than the caregiver can provide, long-term care placement such as a nursing home must be arranged. This responsibility also falls to the caregiver.

Nurses often are in contact with caregivers of persons with Alzheimer's disease in physician's offices, hospitals, nursing homes, and support groups. This affords nurses an opportunity to assist these caregivers in providing care to the person with Alzheimer's as well as address the personal needs of the caregiver. The purpose of this paper is to review articles describing the use of qualitative research to identify and address the unique needs of caregivers of persons with Alzheimer's disease.

Qualitative Research on Caregiver Skill Development

Caregivers of persons with Alzheimer's disease require the development of skills appropriate to this task. One qualitative study examined how "caregiving issues and skills developed over time in family caregivers of persons with Alzheimer's disease" (Paun, Farran, Perraud, & Loukissa, 2004, p. 242). The aims were to (a) identify caregiving issues that emerge over time; (b) examine the development of caregiving skills; and (c) identify additional skills needed by caregivers to respond to caregiving issues (Paun et al.). This qualitative descriptive study was part of a larger five-year clinical trial where the effectiveness of Caregiving Skill Building treatment interventions was compared to Information and Support Only interventions. For the qualitative portion of this study, researchers met with groups of caregivers in the Chicago metropolitan area plus two rural areas at six and twelve months during the interventions for two-hour sessions where caregiver responses to issues were discussed. After meeting with the group of caregivers, the facilitator typed a summary of comments given by participants (N= 272) in reference to caregiving issues. Twenty-nine summaries were obtained from the group cohorts. The data was analyzed using content analysis. From the data, three major categories emerged: (a) care recipient issues; (b) care giver issues; and (c) resource issues.

Participants identified ongoing development of numerous skills needed to provide care to persons with Alzheimer's disease (Paun et al., 2004). Caregivers reported the continuing decline of persons with Alzheimer's disease. In order to effectively deal with the decline, caregivers needed skills of awareness of signs and symptoms of cognitive decline, skills in either reorienting, distracting, or redirecting, and patience (Paun et al.). One participant remarked about his mother, "She is more confused and disoriented and I learned distracting her works best" (Paun et al., p. 243). Caregivers also described a range of emotional and behavioral changes that accompanied the cognitive decline and suggested skills to use in dealing with these changes. Distracting by involving the care recipient in simple activities such as folding washcloths or going outdoors for a walk proved successful for some caregivers. Many of these approaches were learned during interventions from educational materials or from peers (other caregivers) or just from trial and error or problem-solving (Paun et al.).

Caregiver issues included learning new information about the disease, caring for a person with Alzheimer's disease, and about caring for themselves (Paun et al., 2004). Caregivers reported learning that support group attendance offered them a sounding board and was a resource for emotional support. They also reported the importance of gaining an understanding of the signs and symptoms of the disease. With this understanding, caregivers found it easier to "let go of the old person" and emotionally accept their loved one's limitations resulting from the disease (Paun et al.).

The importance of maintaining humor and spiritual strength was reported by many caregivers (Paun et al., 2004). The value of spiritual strength was also noted by Paun (2004) who documented spirituality as a source of strength for caregivers of family members with Alzheimer's disease. Paun's descriptive study used a phenomenological approach to gain understanding of the caregiving experience and explore the caregiver's perception of motivation and meaning attributed to the experience.

Maintaining caregiver mental and physical health was reported as paramount to caregiver well-being (Paun et al., 2004). Visiting a mental health provider was reported as beneficial to caregivers who experienced depression. One caregiver reported rewarding herself with a lottery ticket for keeping calm during stressful periods in caregiving. The most often reported physical self-care skills included regular walking, practicing yoga, or joining a health club (Paun et al.).

Resource issues surfaced as a category of concern for caregivers. The most frequently used resources were adult day care, respite care, and enlisting additional help from paid caregivers, friends, or other family members (Paun et al., 2004). Many caregivers reported initial resistance or hesitancy in using resources such as adult day care; however they also described feeling relieved after their loved one started attending as this was the only time the caregiver had time for self. The value of respite care and achieving a mental break was also documented by Teitelman and Watts (2004). A phenomenological, qualitative study was conducted by Teitelman and Watts to explore the essence of respite for caregivers of persons with Alzheimer's disease. Researchers discovered that "the essence of respite was more than mere physical or temporal distance from the loved one. True respite involved experiencing a mental break from concerns about caregiving" (Teitelman & Watts, p. 253).

Paun et al. (2004) also identified additional skills needed by caregivers. Skills in anticipating changes in the care recipient's disease process, behavior, and needs would benefit caregivers (Paun et al.). Needed skills related to caregiver issues were identified as dealing with emotional responses to caregiving, understanding the connection between emotional responses and caregiver physical health, and developing a program for self-care. Maximizing resource use for caregiver and care recipient and for researching nursing home placement well in advance of the need for placement were identified as essential skills for caregivers (Paun et al.).

The more skilled the caregivers, the more effective they were in providing care to the person with Alzheimer's disease and taking care of their own physical and emotional health. The less skilled the caregivers, the more tendency to neglect their own physical and emotional health needs. It is important for nurses to understand that skill development is a dynamic, complex process that takes time (Paun et al., 2004). Nurses must obtain a baseline assessment of skills possessed by the caregiver and use this information to individualize interventions needed for skill development.

Qualitative Research and Post-Nursing Home Placement Caregiver Burden

Another issue of importance to caregivers of persons with Alzheimer's disease is coping with caregiver burden after nursing home placement. Caregiver burden does not end with nursing home placement of a loved one with Alzheimer's disease. The caregiving responsibilities post-nursing home placement include family visits two or more times a week to assist the family member with activities of daily living such as feeding, encouraging mental stimulation, and monitoring of nursing care (Garity, 2006). In addition, many caregivers continue with the pre-nursing home placement duties of laundry, bill paying with added nursing home and Medicaid requirements, and coordination of physician appointments (Garity).

Coping was defined by Lazarus and Folkman (as cited in Garity, 2006) as “the process of cognitive and behavioral efforts individuals make to manage stressful caregiving situations which tax or exceed resources” (p. 41). Garity reports on a qualitative study to identify how family caregivers coped with the burden of post-nursing home placement of family members with Alzheimer’s disease (Garity). Strategies, supports, and characteristics that facilitate coping are identified in this study. Participants (N=18) were caregivers of family members with Alzheimer’s disease. Each participant’s interview, which took about 90 minutes, was audiotaped. The audiotapes were immediately transcribed verbatim after the interview. The data was content analyzed according to the constant comparative method. “This method of content analysis abstracts qualitative data into concepts and categories, and identifies and tests hypotheses in relation to how the categories are related” (Garity, p. 42).

Findings from this study revealed that positive interactions with significant people increased coping (Garity, 2006). Significant people included the family member with Alzheimer’s disease, other nursing home residents, nursing home staff, and friends or family. Participation in support groups comprised of other caregivers also proved to enhance coping ability of caregivers post-nursing home placement. Support groups provided caregivers with a means of obtaining information about Alzheimer’s disease. Communicating and sharing experiences with other caregivers facilitated increased coping. A caregiver stated, “Everybody is in the same boat... You’re not the only person who has someone with this dreaded disease” (Garity, p. 44).

Many caregivers stressed the importance of positive interactions with the family member with Alzheimer’s disease. One participant remarked, “I’m glad she’s pleased to see me” (Garity, 2006, p. 43). This caregiver also expressed how difficult it will be when the day comes that her loved one doesn’t know her.

The loss of a family member’s ability to communicate was reported as a significant source of stress (Garity, 2006). Caregivers found it difficult to be alone with their family member when they could not carry on a normal conversation. Nurses are encouraged not to underestimate the impact of the patient’s inability to communicate on the caregiver, especially if the trajectory for Alzheimer’s disease is many years. A noteworthy comment by a family caregiver emphasizes this point.

Doctors and nurses don’t seem to understand how hard it is for me to be unable to converse with my mother now that she’s placed. Because I work in the health care field, myself, they tell me I should better understand that this is what happens. But she’s my mother and I want to be able to talk to her about different things the way I used to. (Garity, 2006, p. 44)

As a way to cope with the inability to converse with their loved one, caregivers often communicated with other residents in the nursing home. This interaction with other residents helped lift the mood of the family caregiver. One caregiver described taking her mother to a communal room, sitting with her and holding her hand while talking to other residents (Garity, 2006).

The importance of positive interactions with other family members or friends was reported by caregivers. Supportive listening by friends or family who had also been through similar circumstances proved most beneficial to caregivers. In addition to a

listening ear, friends and family members can provide diversion from the stress of caregiving. Taking walks or going to see a movie with family or friends increased a caregiver's coping by bringing the world back into perspective (Garity, 2006). In contrast, caregivers had negative interactions with family or friends who were not familiar with nursing homes and had negative comments about this setting. Negative interactions after nursing home placement decreased coping in caregivers (Garity).

This study identified additional factors associated with decreased coping. Role disruption from post-nursing home placement caregiving responsibilities resulted in decreased coping (Garity, 2006). Trying to balance family responsibilities with caregiving responsibilities required significant time and energy. To help cope, three participants suggested that visits to the nursing home be scheduled around family and social life, not vice versa (Garity).

Another source of stress, resulting in decreased coping, was guilt over placement in a nursing home. Caregivers often referred to the placement as a betrayal or a broken promise to their loved one. In contrast, four caregivers realized that nursing home placement was better, because the home was able to provide 24 hour safe care for their loved one with Alzheimer's disease (Garity, 2006). The realization was instrumental in increasing coping abilities.

Another factor that decreased caregiver coping was uncertainty about the future (Garity, 2006). Caregivers want to know what their loved one will have to go through. Most caregivers acknowledged fear of not knowing what to expect. Two caregivers suggested that volunteers help transition and tell other caregivers what to expect as a way to increase coping (Garity).

This qualitative study provided valuable information about caregiver coping post-nursing home placement and has many implications for nurses. Because of the debilitating nature of Alzheimer's disease, it is important for nurses to provide family caregivers with knowledge about the disease. The physical and mental deterioration of Alzheimer's disease must be explained to caregivers to help them know what to expect and to decrease guilt over nursing home placement.

Conclusion

This review has demonstrated the use of qualitative research to identify and address the unique needs of caregivers of persons with Alzheimer's disease. No attempt was made to extract and disseminate all valuable findings from these articles. Nurses and other health care professionals working with patients with Alzheimer's disease and family caregivers of persons with Alzheimer's disease could benefit from reading these articles. Qualitative studies offer insight into the lived experience of caregiving of persons with Alzheimer's disease. Galvin, Todres, and Richardson (2005) used a hermeneutic phenomenological approach to study one man's experience as a caregiver for his wife with Alzheimer's disease. This study gave an insider view of the experience and meaning of the caregiving experience. This insider view can "facilitate empathetic understanding in others and ... empower a deeper level of patient-centred [sic] care" (Galvin et al., p. 9). Professionals could increase awareness of specific needs or concerns unique to caregivers of persons with Alzheimer's disease as well as learn about

interventions that could help caregivers cope with the responsibilities and burden of providing care for a family member with Alzheimer's disease.

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